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Competing patient and professional agendas in service development

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Competing patient and professional agendas in service development

Background

Patient involvement in the planning of health services is often promoted as a necessary adjunct to patient-centred care, but it is often assumed that patients will share the same values and agendas for service development as health care providers and commissioners, or that competing views can be subsumed within a meta-narrative of evidence based practice and cost-effectiveness, (Entwistle et al., 1998). Others have questioned this assumption, arguing that patients and professionals may want quite different things from a health care intervention, (Wagner et al., 2005). In this article we explore the differing agendas of patients and healthcare professionals in relation to the development of a community based chronic pain management service.

The prevalence of chronic pain in the UK is estimated to be 13% (Breivik et al., 2006). The cost of treatment places a burden on the National Health Service (NHS), with the care costs for back pain alone exceeding £1.6 billion per annum, (Maniadakis and Gray, 2000). The costs to sufferers, informal carers and the wider economy are also significant, creating a strong impetus towards the development of more cost effective interventions.

Government has responded by promoting 'self-management' approaches, such as the Expert Patient Program (EPP)(EPP Evaluation Team, 2005). A recent, UK-based, randomized controlled trial of EPP in 812 patients with osteoarthritis showed small improvements in anxiety and self-efficacy but no improvement in pain, physical functioning, or GP visits (Buszewicz et al., 2006; Kennedy et al., 2007; Griffiths et al., 2007). Current approaches to self-management are based in part on social cognitive theory. However, these approaches have been criticized on theoretical and methodological grounds, not least that intention to change is a poor predictor of actual behaviour change (Ogden, 2003; Marks, 2008). Cognitive Behavioural Therapy (CBT) combines insights from social cognition theory

with ideas drawn from behaviourist psychology to generate a different approach to behaviour change and the management of chronic conditions, prompting a debate about whether it is cognitive change or other means of direct behaviour modification that account for the apparent success of the approach, (Dimidjian et al., 2006; Longmore and Worrell, 2007).

Clinical psychology has developed considerably in the 20 years since the design of current self-management approaches (Hayes et al., 2006), and the latest behavioural and cognitive treatments do not adopt a focus on 'self-efficacy', 'positive thinking', or even the necessity of pain control, but rather on changing core processes of suffering and disability, including 'avoidance', 'preoccupation with the past or future', 'verbally-based behavioural rigidity', and 'failures of values-based action'. These approaches recognize that while painful feelings, discouraging thoughts, or troubling memories are ubiquitous in human life, they can often have pathological effects on daily functioning (Hayes et al., 1999; Hayes et al., 2006; McCracken and Eccleston, 2005). A key aspect of their amelioration is the development of 'psychological flexibility' or the capacity to adapt to changing circumstances by focussing on long-term goals rather than short term impulses, (Kashdan and Rottenberg, 2010).

These newer approaches can be referred to as Contextual CBT (CCBT) (McCracken and Eccleston, 2005) and a specific example is called Acceptance and Commitment Therapy (ACT). There is growing evidence of the benefits of this general approach, including six randomized controlled trials (RCTs). Two small-scale RCTs of the contextual treatment processes have been conducted. The first, conducted in Sweden, applied the intervention to persons at risk of long-term disability due to pain, and reported substantial reductions in missed workdays and health care use from four hours of treatment (Dahl et al., 2004; Wicksell et al., 2008). In the UK the intervention has usually been delivered in specialist hospital pain management units, including intensive interdisciplinary services delivered for more than 90 hours. Although three large effectiveness studies of these contextual methods in tertiary care have also been conducted, showing decreased disability, emotional distress, and healthcare use (McCracken and Eccleston, 2005; McCracken et al., 2007; Vowles and

McCracken, 2008), such care is costly and often only available to patients with very severe and long-standing problems. Our hypothesis is that a much broader base of chronic pain patients could benefit from CCBT if it could be provided in a cost-effective and easily accessible community based pain-management programme.

We received funding from the Research for Patient Benefit programme of the UK's National Institute for Health Research [grant number PB-PG-0808-16156] to conduct a small RCT of community based CCBT. Before the trial could commence we needed to re-design the intervention and specify a service provision model that would be feasible in a community setting and which would be acceptable to patients, primary care staff and health care commissioners.

The findings of the RCT are reported elsewhere (McCracken et al., 2013). Here we explore the perspectives of different stakeholder groups on how to best translate and deliver a feasible and acceptable community based pain management service based on CCBT, in order to generate an adapted model for the proposed service, which would be evaluated in a later phase of the research. It is important to note a limitation on the scope of the exercise; our intention was to involve stakeholders in service design, but not in reviewing or developing the basic science on which the intervention is based. This limitation raises several issues that we have discussed elsewhere (Wainwright et al., 2013).

Methods

The study was conducted over 12 months in the south-west region of the UK. The intention was to access shared beliefs, so an approach which allowed for interaction was used rather than individual interviews. Focus group, brainstorming and Delphi methods were reviewed; (Murphy et al., 1998), however, the Nominal Group Technique (NGT) was considered the most appropriate. NGT has been used to elicit professional and patient preferences in other health care contexts, including the development of a diabetes service in primary care,

(Gallagher et al., 1993), and indeed, to assess the needs of people with chronic pain, (Dewar et al., 2003). NGT entails a 10 stage process, which includes participants writing down their key concerns prior to group discussion. All ideas are discussed by the group and ranked and re-ranked according to their perceived importance. The rankings can be analysed and differences between groups identified, and the discussions can be transcribed and thematically analysed. We ran separate NGT sessions for each stakeholder group, to enable differences between them to fully emerge. These differences were analysed, considered and synthesised by the research team. The study was approved by the NHS Local Research Ethics Committee (reference number, 09H010799).

Sampling and Recruitment

Recruitment was through the Primary Care Research Network (PCRN), South West. General Practices were approached and those who expressed an interest were visited by a member of the research team. Practices that agreed to participate were asked to recruit General Practitioners (GPs), nurses and patients with chronic pain (using a database search and mail out). Patients were sent an information sheet and contacted the research team if they were willing to participate. PCRN staff also recruited commissioners from a PCT in the south-west.

Data Collection

Seven NGT groups were conducted, three with practice staff, three with patients, and one with commissioners. The commissioner group was conducted at the PCT headquarters and the others in the premises of participating practices. The groups were facilitated by two researchers. Digital audio recordings were made of each NGT group and transcribed verbatim.

Analysis

Quantitative analysis entailed comparing variations in rankings and weightings between individuals, groups and sub-groups. Digital recordings of the sessions were transcribed verbatim and NVivo was used to aid coding and analysis. Our analytical aims were: to provide a rich description of the issues raised, understand the meanings ascribed to them, and gain an insight into why particular issues were considered more important than others. There are many approaches to coding qualitative data, (Miles and Huberman, 1994), however given the structure of the data collection process and the nature of our analytical aims it was felt that content analysis would be the most appropriate (Green and Thorogood, 2004). The top ten rankings were used as a master coding frame, but within this structure a more inductive and open-ended approach was taken towards the generation of themes.

Results

NGT Group Top 10 Rankings

Table 1 summarises the rankings from the NGT groups. The labels describing the issues reflect the words used by the groups, but our analysis of the qualitative data suggests that similar issues emerged in different groups even though they were sometimes labelled differently, or grouped differently, for example, cost and effectiveness were treated as separate issues by some groups, but linked as cost-effectiveness or cost-benefit by the commissioners. We have attempted to resolve this by using techniques of synthesis derived from meta-ethnography, in which the qualitative data from different groups are analysed to assess the meanings and definitions applied to different categories and labels in order to assess the equivalence of issues raised in different groups (Britten et al., 2002). This is necessarily an imprecise process, but one which is consistent with the usual methods of qualitative synthesis and we have attempted to include sufficient detail to reveal significant nuances of meaning. The findings from this analysis were used to develop schematic representations of the patient and professional agendas, (see figures 1 and 2 below), based on the key themes and relationships that emerged. This necessarily entails a degree of

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3 reduction in order to meet the constraints of a concise and coherent narrative, but
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5 comparison between the schematic figures and the top ten rankings in table 1 reveals the
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7 extent of this process.
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Table 1 Final top ten rankings for each group

RANK	Group 1 (GPs & nurses)	Group 2 (Patients)	Group 3 (GPs & nurses)	Group 4 (Patients)	Group 5 (Patients)	Group 6 (Commissioners)	Group 7 (GPs & nurses)
1 (high)	Cost	Sufferer involved in delivery	Patient selection	Understanding individual needs	Sensitive & approachable staff	Cost effectiveness & cost benefit	Efficacy
2	Location	Support between sessions	Aims and outcomes	Staff training	Quality of venue	Evidence of effectiveness	Accessibility
3	Prioritization & selection of patients	Specialist knowledge	Referral/access	Communication with patient	Physiotherapy involvement	Clinical involvement	Outcome measures
4	Tailor to local needs	Accessing service	Who delivers it?	Management of the service	Information about other services	User involvement in service design	Costs
5	Staff training	Group size	Funding	Aftercare & follow-up	Being treated like an individual	Patient acceptability	Follow-up and maintenance
6	Feedback to GP	Referral criteria	Quality assurance	Characteristics of room	Varying times	Commissioner involvement in redesign	Marketing to GPs & patients
7	Management across practices	Supportive group work	Waiting times	Education for patients	Group size/individual sessions	GP trust in service	Continuity of care
8	Timing	Duration of funding	Follow-up & on-going support	Sharing experiences	Holistic approach	Addressing inequalities	Eligibility criteria
9	Staff time commitment	Transport/parking	Management of unresolved cases	Role of GP	Accessibility	Public health input	Referral pathway
10	Patient motivation	Who provides intervention	Staff training	Opening times	Communication with patient & GP	Clinical governance	Length of treatment

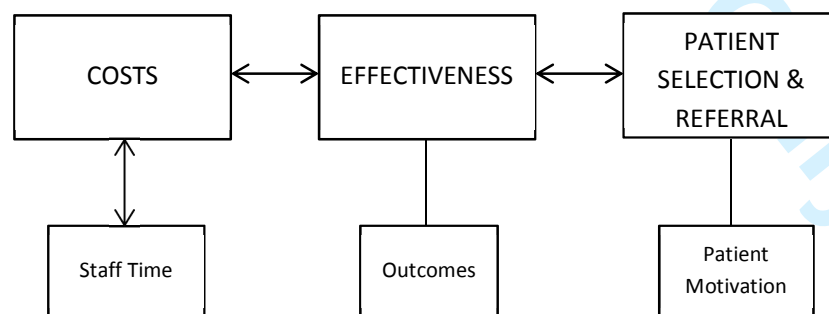
Although each of the groups had a unique top 10 and some themes were discussed by patients as well as by GPs/Nurses or commissioners, it was possible to draw a rough distinction between a patient agenda and a professional agenda, (arguably the commissioners had a slightly different agenda to the GPs/nurses, but we felt that they overlapped sufficiently to be treated as one).

The Professional Agenda

We have listed issues that were of primary importance to the professionals under the heading of the professional agenda, and those that were more important to patients under the patient agenda, but have included insights from patients on issues that fall under the professional agenda and vice versa.

Three key themes emerged: cost, effectiveness/outcomes and patient selection/referral, (see fig. 1).

Fig. 1. The Professional Agenda, (GPs, Nurses and Commissioners)



Costs

Costs or funding were prioritised by all of the GP/nurse groups, as were effectiveness, efficacy and outcomes. Only the commissioner group formally linked them in the category of cost-effectiveness, but the sense of a trade-off between costs and efficacy was also discussed by the GP/Nurse groups. Categories such as efficacy, effectiveness and

outcomes have specific meanings in academic discourse and are far from synonymous; however, they were used more loosely by the groups. We have retained the terminology used by the participants, clarifying meaning where appropriate.

Costs were a concern for all of the professional groups, but the GPs and nurses were particularly exercised by the possibility that additional costs would accrue to the practice:

“...we’re a little bit jaded because there’s a steady trickle of services that were previously provided in secondary care which it’s [now] expected that primary care will do, but no additional funding follows. And there just isn’t any slack in the system. So I think it cannot be perceived by the PCT as a way of saving secondary care funding by just transferring it into primary care without additional funding for it.” (Group 3: GPs/Nurses).

Underpinning this concern was the belief that practice staff might be expected to provide the intervention and that their time might be more effectively used in other ways:

“We’ve already taken some of our secretaries and trained them up as healthcare assistants, to become phlebotomists, and we’ve got healthcare assistants who are doing the anti-smoking clinic. And all the chronic disease management is done by nurses. There’s no slack and I don’t see any GP taking it on.” (Group 3: GPs/Nurses).

However, there was also recognition that the new intervention might generate savings, both for the practice and the broader health economy, by reducing the number of GP consultations, prescribing, and costly referrals:

“If it saved us a number of consultations per year, could be number of prescriptions, number of referrals to secondary care because we’re getting penalised for referring to secondary care.” (Group 7: GPs/Nurses).

Not all participants in the GP/Nurse groups were concerned about costs or savings to their practice, but there was recognition that there were wider costs and savings which might be important to other stakeholders, not least the Primary Care Trust which (at the time of data collection) held responsibility for commissioning:

“I’ve put costs to the patient, cost to the doctor, cost to the health service and tax payer.” (Group 7: GPs/Nurses).

The commissioners appeared to have few doubts about the primacy of containment and the need for new interventions to generate net savings:

“Honestly right now in the current climate it’s how much money is it going to save? That’s what we’re judging it on, because we have this massive income challenge.” (Group 6: Commissioners).

The commissioners claimed that in the current climate of austerity any new service would need to yield a 160% return on investment in order to be commissioned, that is, all the costs of providing the intervention, plus a further 60%, would need to be recouped from savings generated elsewhere. If this claim is valid, it marks a substantial tightening of cost-containment, beyond prevailing definitions of cost-effectiveness. The National Institute for Health and Clinical Excellence (NICE) judges interventions to be cost-effective if they cost less than £20000 to £30000 per Quality Adjusted Life Year (National Institute for Health and Clinical Excellence, 2010). While all of the professional groups had an awareness of the cost-containment agenda, the patient groups barely mentioned the issue, making this a fundamental difference in the professional and patient agendas.

Effectiveness

Closely allied to the question of costs was the theme of effectiveness, most directly as the justification for the costs. The following quotation from the commissioners’ group

emphasises the importance of evidence of effectiveness in persuading stakeholders in the commissioning process that the intervention is worth commissioning:

“What is the evidence behind it? And making sure that your local public health team and consultants understand what you’re doing and are brought into that... so it’s about stakeholder management really.” (Group 6: Commissioners)

The link between costs and effectiveness was also important to primary care staff, although this was often expressed in terms of saving time and resources for the practice rather than as an element of the commissioning process:

“It comes down to efficacy. If you can prove to me that this really works and my work load is going to reduce as a result of this and my referral pattern is going to reduce then that would be quite tempting.” (Group 7: GPs/Nurses)

However, the focus on effectiveness was not purely driven by economic rationality; staff were also concerned with the benefit to patients:

“... you’re not going to get GPs to refer to a service that there’s no firm evidence base. You’re not going to get patients to commit to something that they don’t think is going to help them either so I think you need to be clear about how efficacious it is and what benefits are likely to be gained from it.” (Group 7: GPs/Nurses)

This raises the question of what constitute successful outcomes. Reports comprised a mixture of: resource savings, benefits for patients, and also savings/benefits for the wider society:

“I think there should be a high rate of return to work, reduction in analgesic use [...] you still probably would do the investigations and referrals because we want to make sure there isn’t anything underlying it. But as I say if they’re waiting for referrals and they got better on the therapy, you’d say that was a success.” (Group 3: GPs/Nurses)

Staff were also concerned about the possibility of adverse outcomes, particularly for patients whose symptoms were not ameliorated by the intervention. The question of who would benefit from the intervention leads into the next theme in the professional perspective.

Patient Selection and Referral

A key concern for professionals was how to select patients who would benefit from the intervention and what the referral process should comprise. The aetiology of chronic pain includes physiological, psychological, and social factors with many cases remaining medically unexplained or non-specific. In addition, the planned intervention aimed to change behaviour patterns and improve functioning rather than being curative in intent. This raised questions about who should be referred and when. Some professionals preferred patient self-referral, not least because it was easy for the GP, but most expressed the need for GPs to prioritise patients or ration the service:

“I think we’ve got to be much more up front about rationing [...] this is a service that inevitably isn’t going to meet absolutely everyone’s needs. It’s got to be rationed and therefore you’ve got to ration it to the people who you feel will get most from it and that requires triage.” (Group 3: GPs/Nurses)

The type of chronic pain condition, its duration and the extent to which other interventions had been tried, were suggested as triage criteria, but overwhelmingly participants felt that psychological factors and particularly the patient’s motivation were the key criteria for referral:

“...I’m not sure that you can necessarily alter the level that patients’ motivation is at, to change the situation they’re in, but what you can do is make sure that whoever’s referring is given clear guidelines or is able to select those patients who would appear to be motivated rather than kind of ‘oh my God, what am I gonna do with this patient, let’s just send them on that to get them out of the room’.” (Group 1: GPs/Nurses)

Many professionals used the term “heart-sink” to describe long-term chronic pain patients who had received several interventions without amelioration of symptoms and who continued to consult their GP. It was suggested that such patients often lacked the motivation to overcome their difficulties:

“[There are] those that really want a fix [and] will be motivated, and there’s a group that actually likes the label.” (Group1: GPs/Nurses)

Given that the aim of the intervention is to change the patient’s responses to their illness, it is ironic that responses entailing “negative attitudes” should be seen as a reason not to refer. However, this view was also found among the patients themselves:

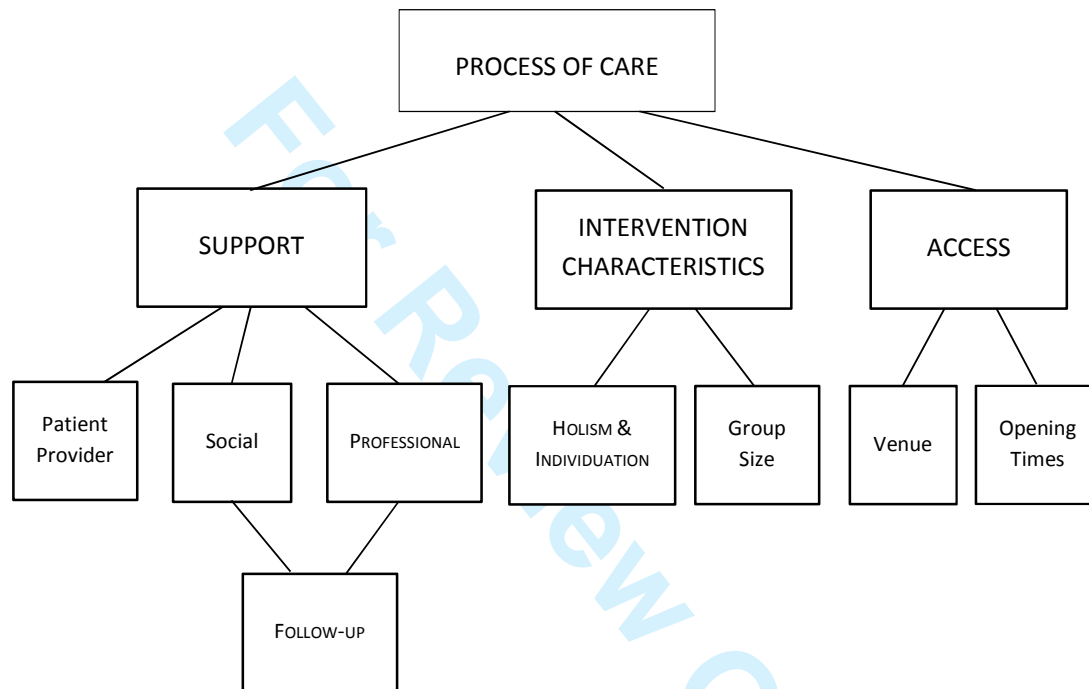
“One of the issues I think is suitability of the patient and the GP’s assessment of that patient as to whether they’ve got a negative approach to it or a positive approach to it. I think if you have a very negative mind-set you’re going to go into this and you’re going to waste NHS funding because you’ve got to the bitter stage and you don’t want help.” (Group 2: Patients)

The dilemma of deciding which patients to refer links with the earlier theme of cost-effectiveness. The intervention was initially developed to enable patients with seemingly intractable chronic pain to improve their functioning by enhancing ‘psychological flexibility’. However, from the narrow perspective of cost-effectiveness it might be considered more efficient to prioritise patients with less entrenched difficulties who may be more likely to respond positively to the intervention.

The Patient Agenda

The patient agenda comprised three main themes: patient support; intervention characteristics; and access, (see fig. 2).

Fig.2. Patient Agenda



The patient agenda could also be characterised as sub-categories of an over-arching theme called 'the process of care', by which we mean the non-technical aspects of service provision and organisation, which include: the location and timing of delivery, attitudes of staff especially regarding courtesy, respect and compassion towards patients, and other non-clinical factors that influence the patient experience.

Support

We have used this broad theme to cover several related topics: empathy and emotional support from service providers, knowledge and advice (beyond the intervention itself), and

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3 follow-up. This theme was of central importance to the patient groups, with ‘access’ and
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5 ‘intervention characteristics’ secondary to it.
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8 The first sub-theme, ‘patient provider’ focuses on the extent to which patients or fellow-
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10 sufferers should be involved in the delivery of the service. A key motive was the desire to
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12 evoke deep empathy from the providers of the intervention:
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15 “I don’t think it really matters per se who would run the session. I rather think that
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17 somebody that’s actually suffered from chronic pain and has had training to stand up
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19 there with your GP or your nurse or whoever and has actually experienced what
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21 you’re going through to one degree or another... but I think that it’s very important
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23 because you can be spoken to and you think ‘you haven’t got a clue, you don’t know
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25 what it’s like’. That would be my main issue.” (Group 2: Patients).
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28 Such a person would be able to inform professional providers of what was achievable and
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30 appropriate and make patients more receptive to the intervention:
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33 “It would probably make you more receptive to what you’re being told, because
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35 you’re not sitting there thinking ‘you haven’t got a clue’.[...] you can talk at me all you
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37 like but if you’ve experienced it I’m going to listen and I’m going to take it on board.”
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39 (Group 2: Patients).
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42 It was suggested that patient service providers might also bring tacit knowledge, gained
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44 through their lived experience of the illness, that might not be available to a professional, but
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46 the problem with knowledge gained from personal experience of illness is that it can be
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48 idiosyncratic:
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51 “...the only problem with that [patient provider] is then you tend to personalise it as a
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53 patient and talk about your erm... You need to be more open to everybody’s point of
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55 view rather than...that’s where the needs of others come in. If you’re doing the
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tutoring then basically you need to be open to other people's needs rather than throw over your own." (Group 4: Patients).

It was also felt that involving patients as providers might not be necessary if professional providers established effective communication with patients:

"But you can have patient involvement through the session anyway; if the people taking the sessions make sure that everybody understands that it's open, that any time if you need to ask questions or you want to say something you are quite welcome to do so and then that way you get patient input as well as get over what you want to say." (Group 4: Patients).

This notion of informal input from patients leads into the next sub-theme, social support. Empathy is an important aspect, but social support extends to other psychological benefits arising from contact with people experiencing similar symptoms and problems. Exchanging practical tips for coping and sharing lay expertise was mentioned in some groups, but more often participants spoke of the loneliness of enduring chronic pain and the support and comfort they gained from talking to fellow sufferers:

"...it's more about emotional support than technical support. [...] I just feel the group sessions can be more effective sometimes, talking to other people, you do feel very alone and just understanding there are other people that have this" (Group 2: Patients).

Most of the discussion of social support was positive, but some negative views also emerged, for instance the claim that extensive discussion of each other's problems might be 'depressing' or a distraction from the actual intervention:

"... all patients obviously need to get their point across and need to be able to ask questions but I also believe that in a lot of meetings that I've been to the people that are giving the session also have a structure to get through and I sometimes wonder

whether it can actually go off track when you all discuss... because I mean we're all so passionate and frustrated about our own conditions that we could probably sit here for hours all of us talking about it to each other." (Group 4: Patients).

Turning to the next sub-theme, professional support; chronic pain patients often feel delegitimized by the suggestion that their condition might have a psychological element rather than being exclusively bio-mechanical, (Wainwright et al., 2006), and prior to data collection we thought that this might make patients reluctant to participate in an intervention delivered by a psychologist. However, this was not the case. Patients were not concerned about the provider's profession, so long as they were well-trained in the intervention and able to build an empathic relationship with the patient, thus continuity of care was considered important:

"And that we can build a relationship with them you know through the group sessions. I think it's important so you don't have to start all over again with somebody else." (Group 2: Patients).

Again, this focus on the quality of the relationship between patient and provider was driven by the desire to generate deep empathy on the part of the provider, not as a desirable add on with little therapeutic benefit, but as a fundamental determinant of the intervention's effectiveness:

"If the people that are dealing with you don't understand what it's like for a person in chronic pain then they've got no right to be...really because there are so many emotions you go through when you're in chronic pain you get angry, you get annoyed, you get frustrated and those can be another symptom on top of your chronic pain. So you need somebody in that position that is going to understand why you feel like this." (Group 4: Patients).

Empathy and understanding were highly salient and often reported as essential requirements, but one patient group raised the point that this should not preclude challenging the patient's perceptions:

"You do need people who are sensitive but sometimes you do need the challenge so it's all about having people with common sense and skills and taking a balanced approach. Being able to weigh up the person they're speaking to I guess is a part of it." (Group 5: Patients).

This point was not widely made, but it does raise an important question about an intervention that is designed to challenge chronic pain patients' perceptions about the limitations and constraints of their illness, but which also relies (in the opinion of many patients) on deep empathy. This tension, between the need to support and comfort vulnerable people and the desire to see them achieve autonomy and optimise their full potential, emerges in many health and welfare contexts. It also emerged in the final sub-theme which concerns 'follow-up'.

The intervention was designed to have a fixed number of treatment sessions without follow-up. Patients questioned this design, first because of their desire to receive on-going emotional and social support:

"Regular contact really, because sometimes you can feel you're alone [...] if you ring [the] pain management [service] a lot of the time it's an answer machine or somebody takes a message for one of them to ring you but that can take several days so just someone at the end of a telephone some days when you are particularly bad." (Group 2: Patients).

Secondly, it was suggested that the effects of the intervention might wear off over time, or that symptoms might return and require further attention:

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3 “...it would be nice if it is was, ‘okay you’ve done what you can and we think you’ve
4 reached a plateau now but you can drop back into the service 6 months down the
5 line if you have a relapse...when you hit a low’, it would be nice to duck back into the
6 service, ring them up and say ‘look, you know, it’s flared up again, can I come back
7 in?’”
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14 Patients suggested that chronic pain tends to recur and that the curative orientation was
15 therefore less appropriate than on-going support. Up to a point this perspective was shared
16 by some of the professionals:
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21 “...most of these patients have a chronic condition and I suspect that behavioural
22 techniques are a great way of trying to deal with that, but I suspect they need
23 boosting from time to time in this personality group. I would have thought that there’s
24 a good response in the first six months following behavioural therapy and then all
25 those techniques begin to, you get a bit lazy about them and doubt them and there is
26 a fall-off and so I wonder whether with this group if you had an annual refresher
27 course...” (Group 3: GPs/Nurses).
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36 The professional perspective on the need for follow-up may be close to that of the patient,
37 but there are also differences. Professionals tended to see the recurrence not just as a
38 failure of the body, but also in terms of the personality of the patient and the behavioural
39 orientation of the intervention, that is, they recognised the intervention as an on-going project
40 of behaviour change akin to smoking cessation or weight loss programmes:
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47 “Well they’ve found with dieters and weight watchers and smoking cessation and all
48 sorts of things, that if you have a patient helpline the rates of people [...] reaching
49 target is much, much higher than just being left alone in isolation and that’s just the
50 holding hand bit which is a therapy in its own right.” (Group 3: GPs/Nurses).
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56 A more significant difference was the tendency for professionals to recognise that follow-up
57 sessions would add significantly to the costs and possibly extend waiting times:
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3 “... the cost would rocket if you’re adding another group that’s a follow up...how
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5 much would that add to the cost?” (Group 3: GPs/Nurses).
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8 Again, this concern was linked to what is almost a moral judgement about the chronic pain
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10 patient:

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12 “ But then again if you’ve got a massive number of patients you’re going to have to
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14 say how many treatments you’re going to allow them otherwise it’ll just get out of
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16 hand won’t it? [...] That’s when the chronic people would like it to last forever.”
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18 (Group7: GPs/Nurses).
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21 While both patients and professionals recognised the desirability of follow-up, only the latter
22
23 began to make the trade-off with cost-effectiveness.
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26 *Intervention Characteristics*

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29 It was explained to participants that the content of the intervention could not be modified, but
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31 the way in which it was delivered could be. Even so, participants challenged the assumption
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33 that the service should comprise a single intervention (CCBT) and suggested a range of
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35 other interventions that should be bundled with it, including physiotherapy, massage,
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37 hydrotherapy. Often the rationale for this pluralistic approach was expressed in terms of the
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39 need for holism and individualisation, that is the belief that the management of pain requires
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41 an approach that focuses on the whole person, and that therefore a constellation of
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43 interventions tailored to the needs of the individual is required:
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47 “Yeah it is being treated like an individual but it’s also looking at the patient as a
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49 whole. [...] rather than, ‘well you fit into that box so you’re going to have all that
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51 treatment that goes with that condition’. [...] physiotherapy, massage, helps your
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53 body cope and your mind then copes better.” (Group 5: Patients).
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55 It was suggested that health care professionals are not always in agreement with this
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57 approach:
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“It’s the whole, it’s the whole thing but also if you are receiving other...I mean I’ve seen a kinesiologist recently and I’ve been seeing an osteopath for some time and when I spoke to the person that was treating me at the [hospital] she was really dismissive of those treatments and I felt well actually do you know, what you were doing for me wasn’t sufficient, it wasn’t helping me to get to the point that I’m currently at but she was like I say just completely dismissive of these other things that have helped me.” (Group 5: Patients).

The professional groups often discussed the multi-factorial nature of chronic pain, but did not express this in terms of holism or individualisation.

A second characteristic of the intervention discussed by the patient groups was the size and composition of the intervention groups. Preferences for group size varied from 8 to 12, but some participants felt that more than 10 would be intimidating for some members and limit their contribution. There was also discussion about whether carers should be able to attend to provide support for patients, but again there were concerns that this might lead to an intimidatingly large group size:

“... 8 to 10 patients or 8 to 10 patients and partners? Because if you start adding the partners all of a sudden the groups become very big and unmanageable.” (Group 2: Patients).

There was no clear conclusion to this dilemma, although it was suggested that carer involvement might be allowed under particular circumstances, but not be routinely offered. It was also suggested that the intervention might be offered on an individual basis to patients who were too vulnerable to join a group. However, there was also recognition that the smaller the group size the longer patients might have to wait to access the intervention:

“If you keep it too small, like the [hospital based pain management service], you’re waiting up to 18 months to get on a coping skills [course]. If it’s [a group size of] 4 or whatever it’s going to take forever isn’t it?”

This was the only area in which the patient groups raised the trade-off between service quality and resource constraints, although it is expressed in terms of waiting times rather than costs.

Access

We have already noted concerns about waiting times, but this theme relates more to physical access, including the geographical location of the service, transport to and from it, 'opening times' and the extent to which the venue was adapted to meet the needs of patients with chronic pain. The aim of the study was to evaluate the transfer of the pain management intervention from the tertiary care setting, into local communities, thereby improving geographical accessibility. There was broad support for this objective, but considerable discussion about 'how local' the service should be.

"If you choose a GP surgery you've got to stay local to you so if it's held at a GP surgery you're 99.9% sure you can get there. [...] But if it's in Oxford you're not going to bother. [...] It's going to take so much longer out of your day. It might take you an hour to get there and an hour to get home..." (Group 2: Patients).

Some of the groups tried to quantify the distance that patients might be prepared to travel, 5 miles was proposed as a maximum, but others felt that distance was less important than good transport links and parking.

"... it's not how far, it's 'can I drive? Can I park close? How much pain inducing movement have I got to go through?'" (Group 2: Patients).

These concerns were shared by the professional groups, who drew on experiences of similar referrals where geographical distance had diminished uptake:

"We send patients off for pulmonary rehab and all sorts of other bits and pieces and sometimes the uptake isn't good [...] purely because either they can't drive or they can't get there and they want something on their doorstep." (Group7: GPs/Nurses).

A further sub-theme was the suitability of the venue for patients with chronic pain many of whom have limited mobility and often find remaining seated for lengthy periods very uncomfortable; several practical requirements were identified: that the service be located at ground level to avoid stairs; a range of different types of furniture because what is comfortable for one patient might not be for another; sufficient space for patients to get up and walk around; provision of somewhere to make drinks during breaks; easy push doors and disabled parking.

Finally, the scheduling of the sessions was highly salient for the patient groups, but no consensus emerged due to the varying needs and preferences of participants:

“Unfortunately some people are better in a morning, some people like myself are better in an afternoon. If you’re working how on earth are you going to do a 6 week course if it’s mornings or afternoons. You’d have to have a very understanding employer who’d let you go for 6 weeks.” (Group 5: Patients).

It was suggested that the intervention should be made available at a range of different times, including out-of-hours, and that patients should be able to choose an iteration that was suitable for them.

Discussion

Our analytical conceit is that a patient agenda can be differentiated from that of health care professionals. Before discussing these agendas, it is important to state some caveats. First, the agendas are not mutually exclusive; professionals expressed some of the concerns of the patients and vice versa, albeit often with different nuances of meaning and differing degrees of salience and priority. Nor is it the case that the two groups unequivocally subscribed to the agendas we have attributed to them – as with any group, there were individual differences of opinion and emphasis. We have attempted to illustrate the overlaps and internal disagreements in our presentation of the results. What remains are two broadly distinguishable standpoints.

Our analysis suggests that the primary concern on the professional agenda is cost-effectiveness, while the primary concern on the patient agenda is the process of care. Among the professionals the commissioners were particularly exercised by the necessity of new interventions generating absolute savings. The generation of savings was raised by other professionals, but more often in terms of cost-containment, particularly for the practices to which they were attached. All of the professional groups were concerned that the intervention should be based on sound evidence of effectiveness and achieve optimum health gain for the resources invested.

It is striking that cost-effectiveness was far less salient to the patients. Some were concerned that small treatment groups or extensive follow-up might increase waiting times, but this was rarely articulated in terms of financial costs. In the UK most health care is funded through general taxation and largely free at the point of delivery, which may explain why costs were not salient to the patients. When the NHS was established health care professionals were also putatively sheltered from consideration of the costs of their practice; our findings support the claim that the marketization of the health care economy has heightened their awareness of costs (Frith, 2013). Since April 2013 Clinical Commissioning Groups have been established with the aim of involving GPs and other health care workers more directly in budgetary management. This initiative has not yet been fully evaluated, but evidence from the GP fundholding initiative of the early 1990s suggests that involvement in budget holding can increase awareness of costs at least for some GPs, (Wainwright and Calnan, 2011).

The professionals' concern with effectiveness is also explicable by reference to the commissioning process (which GPs are increasingly involved in) and the broader rise of Evidence Based Practice within professional discourse (Broom and Adams, 2011). But why were the patients apparently unconcerned by the effectiveness of the intervention? There are several plausible reasons. We briefed participants that there was an established evidence base relating to the effectiveness of the intervention in the tertiary care setting and

patients may have assumed that this could be generalised to the primary care setting, or that the NHS simply would not provide an ineffective treatment. More contentiously, many chronic pain patients have a long history of on-going symptoms, multiple referrals and uptake of interventions that have had limited effectiveness in ameliorating their symptoms; might it be that many of them no longer prioritise the pursuit of an effective 'cure', and are more concerned with obtaining deep-empathy and emotional support from service providers?

We use the 'process of care' category to span a range of factors relating to the lived experience of receiving an intervention. Some were practical, for instance, opening times, and the comfort and location of the venue. But the process of care factors about which the patients felt most strongly were affective rather than practical, for example, the desire to evoke deep-empathy from service providers, the emphasis on emotional/social support and on-going follow-up. These factors were not reported as desirable additions to the therapeutic content of the intervention, but as essential pre-requisites or even intrinsic elements of the intervention. Many of the patients did not appear to be seeking a 'cure' for their symptoms, but rather a degree of understanding, sympathy and support that would strengthen their capacity to endure their suffering. These findings are consistent with the literature on 'peer support' which Dennis has reviewed, offering the following definition: "peer support, within the health care context, is the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person." (Dennis, 2003: 329).

The professionals were often aware of this orientation towards on-going support rather than curative medicine among chronic pain patients but tended to construct it negatively, for example, through references to 'heart-sink' patients, who 'like the label', and the need to

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3 refer patients who were motivated to recover, rather than wanting the intervention 'to last
4 forever'. This negative construction may stem from the desire to avoid the 'emotional labour'
5 that on-going support for patients with chronic problems entails (Larson and Yao, 2005). It
6 may also stem from the curative orientation of the bio-medical model and the moral
7 imperative for patients to relinquish the 'sick role' at the earliest opportunity (Parsons, 1951).
8 These expectations do not always fit well with chronic illnesses where the best achievable
9 outcome is often satisfactory adaptation or coping (Parsons, 1975).
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19 There is a tension between the professional agenda driven primarily by cost-effectiveness
20 and the patient agenda that prioritises the process of care, but can this tension be resolved?
21 Theoretically, the two are not incompatible. If process of care factors can be costed and their
22 contribution to the achievement of outcomes such as independent functioning and wellbeing
23 can be measured, then they can be evaluated and compared with any other health care
24 intervention. However, in practice even if the process of care can be shown to improve
25 outcomes, it is perhaps unlikely that an intervention with open-ended follow-up and labour
26 intensive social/emotional support would fare well in a commissioning process driven by the
27 desire to maximise health gain within scarce resources, when compared with short-duration
28 lean interventions that offer more 'bang per buck'. Indeed, the rapid increase in the
29 availability of CBT interventions is substantially due to the claim that they can achieve
30 positive outcomes quickly and cost-effectively. The *Improving Access to Psychological*
31 *Therapies* initiative which has substantially increased the provision of CBT in primary care,
32 came about largely because of Richard Layard's successful attempt to persuade the
33 previous Labour government that every £1000 spent on CBT would generate £3000 savings
34 for the treasury, (Layard, 2005). Extending the duration of CBT or addressing other process
35 of care factors might erode that favourable ratio.
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55 Process of care issues top the patient agenda, but for them to be adequately addressed in
56 the design and provision of interventions, evidence of their cost-effectiveness is required. In
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the absence of such evidence, service planners will need to make trade-offs between cost-containment and patient satisfaction. Our methodology did not allow for such trade-offs to be put to participants in a structured form. However, such techniques are available, for example, Conjoint Analysis (Ryan and Farrar, 2000) which forces participants to make trade-offs between, say waiting time and the distance travelled to access a service. There may also be value in bringing together patients and professionals in joint focus groups, and other deliberative processes, such as citizen's juries, deliberative polls and consensus conferences, to see if the gap between their different agendas can be bridged through the critical exchange of information and discussion, (Culyer and Lomas, 2006). However, these techniques should be used with caution, lest they become a means for manipulating patients into contributing to a discourse of consumer preference that does not reflect their actual beliefs and may not be in their interests, (Wainwright, 2003).

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